

**INDEX OF DOCUMENTS**  
**CONSUMER TASK FORCE**  
**MAY 22, 2007**

EXECUTIVE COMMITTEE MINUTES

PROJECT UPDATES FOR MAY

WHEN CPIGS FLY

OFFICE PROJECT CONTACT LIST

ROBERT WOOD JOHNSON - CASH AND COUNSELING

**CONSUMER TASK FORCE  
EXECUTIVE COMMITTEE  
MAY 11, 2007  
MINUTES**

IN ATTENDANCE: Laura Hall, Jacqui Day, RoAnne Chaney

**Purpose and Composition of the Executive Committee**

The meeting began with a discussion of the purpose of the Executive Committee. Laura shared that as chair, she would like to be the voice of the executive committee, with decisions being made by the group as a whole. It was decided the Chair should make the Consumer Task Force Meetings meeting run smoothly, on time, and with the agenda. The meetings should be “safe areas” where people should be free to talk without fear of retribution. There was also talk about who might be missing from the Executive Committee. There should be someone from the aging community on the Executive Committee. It was suggested that Jack Vint and/or Esther Van Hammen be invited to join.

**Informational Sessions**

As questions arose, RoAnne helped define secondary and primary consumers, managed care, and waivers. It was noted that, at times, it can be difficult for consumers to follow all of these concepts when we are not accustomed to working with them everyday. It was suggested that we hold several informational sessions informational sessions to provide basic information on waivers, grants, managed care, and the LTC 1915(b)(c) waiver concept paper. These sessions would help bring everyone to the same page and would be a good way of orienting new people who wish to join the Consumer Task Force.

**Other Resources for New Members**

The Consumer Task Force binder includes a large amount of information and can be overwhelming to new members. Possible changes included deletion of past minutes. These could be obtained upon request. Include

only the needed information with a glossary of terms/acronyms. Revise the binder to be more consumer-friendly. A directory and member introduction to the binder was suggested.

### **Agenda/Meeting Process**

Possible agenda items include:

- Person-Centered Planning Draft Guidelines
- Project Updates
- Executive committee updates
- Orientation to one concept (grant, waiver, etc)
- Outreach methodology
- Consumer introductions/background
- Meeting length

There was talk about changing the project updates, doing more focused verbal updates that would include a discussion of what's new, what the current issues are, and what input is needed from the Consumer Task Force. Flip charts may be used more often.

It was also noted that one way for getting consumers to be more involved more is to have each consumer tell about their backgrounds and problems they have faced. This would provide a better understanding of people's input and prospective.

It was decided that the Executive Committee would meet after the Consumer Task Force, given the room would be available.

**CONSUMER TASK FORCE**

**UPDATE OF PROJECTS**

**MAY 2007**



## Medicaid Infrastructure Grant (MIG)

### Medicaid Infrastructure Grant (MIG) Update:

There are presently 966 Freedom to Work (FTW) participants. This is up from 964 last month.

MSA rescinded its response to CMS addressing the CMS question about the flat rate payment to foster home care providers when it learned that CMS would not accept this response and thereby would disapprove the state plan amendment (SPA). Rescinding this request allows the SPA process to continue as MSA seeks to work with CMS and resolve this issue seen as bundling. It is noteworthy that the unwillingness to approve the SPA has nothing to do with having personal care services in the workplace which is the core criteria to be fully eligible for a MIG. Michigan MIG specific terms and conditions of the grant state that “By July 1, 2007, the state will set up a conference call with its CMS project officer and present evidence that the state has or will meet the criteria for full eligibility (personal care services at the work place in the SPA) by the end of the year (2007).” Joe learned on May 11, that the CMS Grants division is expecting an approved SPA from its CMS eligibility counterpart by October 1, 2007, and implementation by January 1, 2008. Mike Head, Ed Kemp, & Joe Longcor are setting up a conference call with CMS Grants officers to see what else may be considered. Some advocates have offered to contact CMS and others seeking for a resolve as well. These advocates are awaiting the call with CMS Grants to determine how to proceed.

MIG staff learned that it will not be possible to move the large number of AD Care participants to FTW in time to seek a larger grant. We continue to pursue a smaller number (600-800) of

AD Care participants that presently already exceed the income limits of AD Care, but whom have not previously been removed from AD Care. FTW is clearly the beneficial category for these individuals if they need Medicaid. Otherwise these individuals would need to meet spend downs to secure their Medicaid. The MIG presently anticipates seeking a Continuation report/update due by August 16, 2007.

Theresa downsized the MSA/MIG issues grid reflecting the last two months of action on each topic. Please contact Theresa at [arinit@michigan.gov](mailto:arinit@michigan.gov) if you have questions about the history of an issue. The MSA/MIG group is focusing on the aging out issue as well as other issues that may need to be included as a disregard to the SPA to better support persons in FTW/MBI.

Bryon MacDonald with the World Institute on Disabilities in California met with 34 individuals on May 9, at Disability Network/Michigan to present on Disability Benefits 101.org ([www.db101.org](http://www.db101.org)). This California specific online tool encourages and informs people about work and how work is likely to affect a person's benefits. Attendees were mostly optimistic and favorable. Joe Longcor is to coordinate a webinar or another presentation in the near future with mid to upper level administration to better determine Michigan's interest in a similar on-line tool.

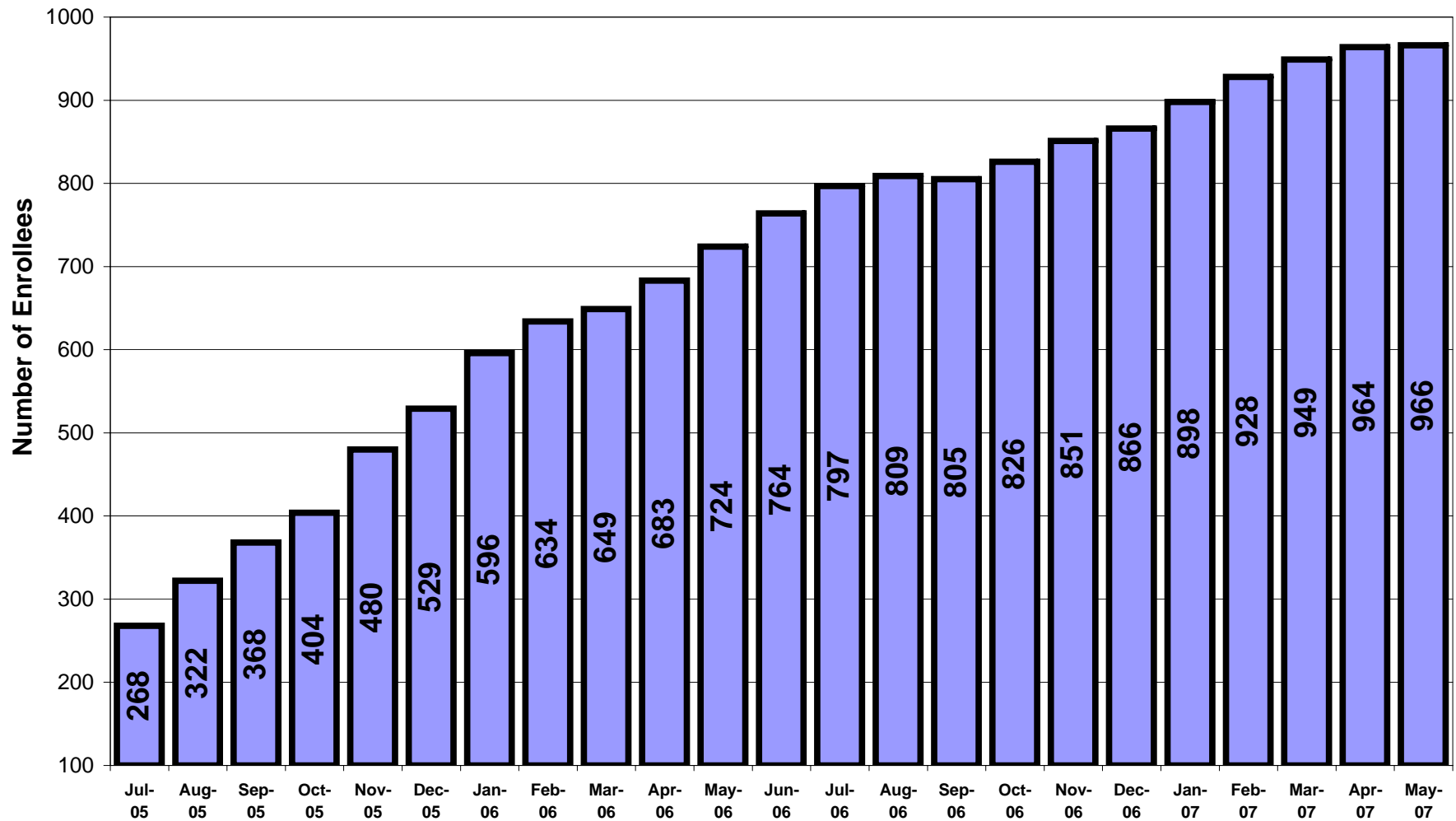
Freedom to Work Enrollment  
By County  
May 2007

County Code	County Name	Beneficiary ID		County Code	County Name	Beneficiary ID
1	Alcona	2		40	Kalkaska	3
2	Alger	1		41	Kent	84
3	Allegan	10		43	Lake	1
4	Alpena	1		44	Lapeer	7
5	Antrim	3		46	Lenawee	11
6	Arenac	3		47	Livingston	8
7	Baraga	1		49	Mackinac	1
8	Barry	4		50	Macomb	58
9	Bay	36		51	Manistee	5
10	Benzie	3		52	Marquette	9
11	Berrien	31		53	Mason	7
12	Branch	8		54	Mecosta	8
13	Calhoun	18		55	Menominee	4
14	Cass	2		56	Midland	14
15	Charlevoix	7		57	Missaukee	1
17	Chippewa	9		58	Monroe	15
18	Clare	2		59	Montcalm	1
19	Clinton	2		60	Montmorency	2
20	Crawford	1		61	Muskegon	41
21	Delta	10		62	Newaygo	10
22	Dickinson	4		63	Oakland	85
23	Eaton	14		65	Ogemaw	1
24	Emmet	8		66	Ontonagon	1
25	Genesee	26		67	Osceola	4
26	Gladwin	1		68	Oscoda	1
27	Gogebic	4		69	Otsego	8
28	Grand Traverse	19		70	Ottawa	19
29	Gratiot	5		71	Presque Isle	1
30	Hillsdale	6		72	Roscommon	5
31	Houghton	5		73	Saginaw	8
32	Huron	5		74	St. Clair	15



County Code	County Name	Beneficiary ID		County Code	County Name	Beneficiary ID
33	Ingham	37		75	St. Joseph	11
34	Ionia	3		76	Sanilac	5
35	Iosco	2		78	Shiawassee	8
36	Iron	4		79	Tuscola	3
37	Isabella	7		80	VanBuren	7
38	Jackson	11		81	Washtenaw	38
39	Kalamazoo	56		82	Wayne	81
				83	Wexford	2
					<b>TOTAL</b>	<b>966</b>

## Michigan FTW Enrollees May 2007



Issue	Explanation	Potential Solution	Action/Timeframe
<p><b>PAS/PCS Issue</b></p> <p>As of today Persons needing PAS/PCS to manage personal needs while at work cannot accomplish this.</p>	<p>Persons needing PAS/PCS to accomplish personal needs are limited at how long during the day they can be away from home. <u>Because they cannot take care of personal needs at work, they end up working less or choosing not to work at all.</u> The FTW law itself prohibits the use of PAS/PCS in the work place, ie “FTW 106a (3) - ...and does not include personal assistance services in the workplace.”</p>	<p>-Work with MSA to draft language to amend the State Plan. This will be part of our Medicaid State Plan.          -The State Plan Language will override the FTW Language.          -Mike, Joe and Theresa will work with MSA          -If no word on SPA by Friday, June 16, Ed Kemp will initiate contact with CMS to ensure the SPA process is moving.</p>	<p>-April 11, 07 Ed Kemp provided an update on the status of MSA's response to CMS. CMS has informally approved all but one response. The remaining issue is in relation to personal care provided in an adult foster care facility. CMS is viewing this service as a bundled service and that MSA is not reimbursing the provider of care. This is not an easy issue to resolve. Theresa will work with the MIG technical assistance staff to determine what other states are doing. This issue also affects the mental health system. This is a critical component to the existing grant and possible submission of the comprehensive grant.  <b><u>-MAY 09 An update was given by Ed Kemp who said that CMS wants us to re-look at the reimbursement issues. An attempt was made to try to separate these issues from the rest of the SPA and move on with the part we are concerned with which includes PA services in the workplace, but the attempt did not fly with CMS. Therefore the whole submission was pulled back in order to stop the clock so we would not have to start over.</u></b>          Ed Kemp stated that he wanted to get started with a committee to resolve these issues next week, he suggested a few individuals who might serve along with someone at least from our group appointed by Mike. He really didn't foresee a speedy result from this committee.          When asked what advocates could do to help, Ed stated that if someone could get the grant people at CMS to talk with the contract policy people and get them to accept an expressed clear effort in the right direction as good enough, maybe that could save the grant.</p>
<p><b>Case Review/Earnings Level Issue</b></p> <p>Presently, after 12 months a person earning over SGA – upon their yearly DHS case review, the person is seen as “not” disabled, and kicked</p>	<p>DHS defers to PEM 260 for directive as to yearly review and PAM 815 as to guidance on the process of review. <u>DHS Diary Date set for automatic annual review of a person with a disability set at one year. The review looks at earnings, then disability.</u> The current FTW law supports this. The FTW law states eligibility standards in 106a (2)</p>	<p>-Working with MSA, and DHS – MRT Division.          -Short term solution “interim update” to DHS proposed.          -Long-term procedure being determined.          - Need to review cases w/out considering disability.          -Need to change procedure manual (PEM) manual to disregard earnings consideration in the case of FTW participants</p>	<p>-Nov 14, 06 Linda reviewed cases in September and the forwarded the re-determination dates as appropriate. There is a new Joint Manual Process that is slowing the process of getting the necessary new policy in place. Therefore, MSA will continue to work with DHS to extend review dates as necessary. In January 2007, the topic will be brought up again to see where things are at that point.          -Feb 14, 07 This issue is still not resolved, therefore Linda is to push review dates forward for six months again. Logan will send Linda an email to see if she has been able to complete the process. If Linda cannot get to it before leaving for her time off work, Logan will ask Anne Bialke to</p>

out of FTW because of earnings level.	specifically “(a).... or would be found to be disabled except for earnings in excess of the SGA level as established by the U.S. SSA”	<ul style="list-style-type: none"> <li>- Jackie &amp; Theresa assigned to work with MSA &amp; complement process</li> <li>-Theresa will assure that Linda does receive copies of the documents she needs (PEM 260 &amp; 174).</li> </ul>	complete the push forward of review dates process.
<b>Unearned Income Issue</b>  Current FTW individuals receive or achieve unexpected unearned income, placing them in a status with unearned income above FPL.	<u>Some unearned income results as a direct benefit from working,</u> such as: unemployment, workers compensation, and working at higher earnings, thereby increasing the amount of SSDI check received in the case of temporary layoffs or medical leave. <u>Other factors that could cause an unexpected rise in unearned income include the death of a parent, receipt of child support, or receipt of spousal support.</u> FTW Law 106a (2) (c) states, “The individual has unearned income level of not more than 100% of the current federal poverty guidelines.” Yet this seems to contradict with 106a (4) (c) which speaks to “temporary breaks in employment that do not exceed 24 months if temporary breaks are the result of an involuntary layoff or are determined to be medically necessary.” <u>Because of a person’s past work record, the amount of unearned income collected during these temporary breaks from employment may actually bring a person above the FPL threshold and make them ineligible to participate in FTW.</u>	<ul style="list-style-type: none"> <li>-The benefits derived from working are received as unearned income, ie unemployment, comp pay, disability leave, etc.</li> <li>-The intent is not to be penalizing people who work</li> <li>- Theresa assisted by Joe, will develop list of items to be included in future inclusive FTW disregard for submission to Logan by June 30.</li> </ul>	<p>-<u>April 11, 07</u> Key concerns of unearned increases that would potentially stop a person’s FTW eligibility include COLA, increased SSDI check due to increased work, increased SSDI (DAC) or a Veterans payment due to a parent’s death, as well as worker’s compensation. There was discussion regarding the ability to disregard unearned income for recipients vs. applicants. Per federal regulation, recipients and applicants must be treated the same, so any disregard for one applies to the other. MSA will pursue this with their administration. Two alternatives were raised: 1) allow unearned income to be part of Freedom Accounts. This will require a State Plan Amendment. 2) Revise the Freedom to Work law to not count unearned income in the eligibility determination and possibly require a flat rate premium (much like MICHild) as this would be easier and cheaper to administer.</p> <p><b>-MAY 09 Theresa asked Logan for an update on the submitted disregards. Logan stated there had been no movement on them. Theresa asked if there was anything that she could do to assist. Logan stated not at this time.</b></p>
<b>Aging Out Issue</b>  FTW participants approaching age 65+ accumulating resources, savings,	FTW Law specifically states in 106a (2) (b) “ <u>To be eligible, “the individual is at least 16 years of age and younger than 65 years of age.”</u> Michigan’s Medicaid Buy-In	<ul style="list-style-type: none"> <li>-One course of action could be to try to pass a Medicaid Buy-In under the Balanced Budget Act as other states are attempting to do. The Balanced Budget Act allows for all ages to participate but has other restrictions</li> </ul>	<p>-<u>April 11</u> Joe noted that we need to have this on the agenda for May so it isn’t forgotten. Per TTWWIIA regulations, a consumer is ineligible for Freedom to Work at the age of 65. It appears to be unfair to encourage a consumer to work only to have to loose all they have gained once they reach age 65. Connecticut has resolved this</p>

retirement, etc. must now dissolve these resources in order to retain Medicaid eligibility.	Law is authorized under the TWIIA, which has an age limit for participation of 16-65.	as to income earned and savings. -Theresa will discuss with NCHSD and look into which states either have done this or are about to accomplish the passing of both. -Theresa will follow up with NCHSD and/or Connecticut on this topic.	barrier using the Balanced Budget Act. Theresa will pursue Connecticut's language. <b>-MAY 09 Theresa outlined the Aging Issue again and asked if the group was still in agreement that the solution was to use the 1902R2 to write an exception to the current policy. Logan stated that this was correct. Theresa asked what Logan needed from us to go ahead with the exception. Logan said just write it up and send it to me. Tony wanted to know if we could do the same with the marriage penalty issue, and the income disregards such as veterans etc. Theresa then asked again about the listed disregards spoke of earlier. Logan responded by saying that it might be possible to include those also in one packaged disregard exception list.</b>
<b>Premium Issue</b>  The current FTW premiums fees are seen as "cliffs." The variance in premium amount leaves big differences from one level to the next, which can be triggered by a simple .50 cents increase in pay.	The FTW Law allows for Medicaid Buy-In premiums to be on a sliding scale. Specifically the FTW Law states in 106a "(5) (c) "the Premium sliding fee scale shall have no more than 5 tiers." <u>An unintended consequence of setting the fee scale as MI did (using an SSI methodology for counting income) resulted in individuals having to earn around \$4,000 a month before paying the first level of premium, which was set at \$50.00.</u>	- Consider a MSA Administrative Policy Change in the existing current premium fee scale. -One Suggestion includes changing to a % scale for individual income level; or go from 100% FPL To 250% of FPL to begin paying premium. - Another possibility would be to switch to a sliding scale based on percentage of countable income. -Some states have premiums that start at the point of any earnings and/or may include unearned income	<u>-Aug 15</u> It was suggested that we consider using % for eligibility into the program. And it should also be noted that % was suggested here as a way to make premiums smoother from one level to the next. <u>-Sept 12.</u> It was suggested by Tony that we might want to look at and compile suggestions using different premium scales or methodology for premiums. Theresa will assist by providing an analysis from NCHSD on what other states have for their premium systems.
<b>Marriage Penalty Issue</b>  The FTW participant's earnings are "deemed" to the spouse and the spouse becomes ineligible for Medicaid and other supports.	The issue of deeming is a problem for FTW participants who have a spouse receiving supportive benefits, such as SSI, due to a disabling condition. A part of the working spouses' income is deemed to the other spouse. This results in the other spouses' benefits possibly being reduced or eliminated.	-This is a federal challenge within SSA -The WIAG group meets in Chicago and this is a topic they are considering. Tony Wong, Karen Larsen, & June Morse participate.	<u>-Aug 15</u> A question was raised, why we couldn't use the provisions in 1902 to specify this group individually, and make a State administrative rule that would eliminate the problem of deeming between spouses. Logan referred us to a piece of guidance issued from CMS that may be of help. More research to be done in this area. Sept 12 Tony is going to write up a possible state solution to this Federal problem using the 1902 (r) (2) provisions. He would like some feedback on a document he is preparing for the WIAG committee.
<b>Part B Premiums Issue</b>	The state DHS policy FTW, PEM 174, clearly states,"a	-Theresa will further research potential implications of this factor	<u>-June13 MSP</u> premiums were discussed briefly as the issue also involves concurrently eligible for ADCARE. Linda

Some FTW persons become responsible to pay the Medicare premium for Part B without being advised of this impact.	person eligible for medical assistance under FTW is not eligible for ALMB.” FTW participants may be required to pay Part B costs when they achieve certain earnings levels. Currently Individuals are not made aware of this before switching to FTW.	within the FTW program -Consider whether a change in Administrative policy is needed -Need to develop method to inform participants that they may be required to pay their Medicare Part B premiums as they begin working.	concurrent with Theresa's findings that people did not have to pay Medicare Part B premiums because of switching to FTW, but because of a rise in their income as a result of working. - <u>Jan 10</u> We acquired information at this meeting that there is a new sliding scale to part B premiums with costs starting at \$93.60 plus \$12.50 and with a scale going up from there. At this time there doesn't seem like there would be an impact for our current FTW participants, but that may change if and when we have participants in the higher income brackets.
<b>Waiver Issue</b>  People are asking about being in FTW while using waivers.	People want to be able to remain within a waiver, work, and participate in FTW, but they have been told they can't. People prefer waivers because of the PSA/PCA services. Waivers have a higher income limit to be economically eligible than other Medicaid programs. FTW is an eligibility category and by using the “Freedom Accounts” a person should remain or be eligible for the MI Choice Waiver.	-Discussed with Pam McNabb & Jackie Tichnell. Eligibility would depend on slots and earnings? - Mike Head noted that FTW was an eligibility Category, whereas the MI Choice waiver is a Program Category. -May 18...Jackie forwarded an overview of why we believe FTW should be able to work in conjunction with this waiver	- <u>Jan 10, 07</u> -Mike Head met with Ed in December to address this. Logan did not know if this had formally been addressed. Joe will check with Ed. - <u>Feb 14, 07</u> We can now celebrate success on this issue. People can now participate in both the waiver and FTW at the same time. Joe presented a copy of a memo to the waiver agents giving them direction on the new policy.
<b>Economic Earnings Issue</b>  SSDI recipients that are FTW enrollees remain discouraged from earning over SGA until a person can minimally replace their SSDI check. Ties into the Federal SSA action on SGA. People are unlikely to work in order to have less \$ in their pockets.	People with disabilities work to make money just like anyone else. Individuals are commonly unwilling to accept work that won't minimally replace their check. <u>It costs PWD money \$ to work, in some cases people with disabilities incur large expenses in order to work.</u> In addition, individuals remain concerned of the future need of medical coverage. Some progress has been made in this area through the TWIIA and reinstatement of benefits provision within.	-Need to do research on what it would take to eliminate SGA and allow persons to wean off benefits slowly. -Work with the MI JOB Coalition and others working towards a solution to the issue of SGA - PWDS need to gain skills to qualify for a higher paying job, so they can earn enough to take the leap of faith off the system.	-Feb & April “Think Work” summits suggest growing effort by Mi Jobs Coalition to seek demonstration/pilot grant from SSA to disregard SGA as a standard for persons with SSDI.
<b>Deductible Issue</b>  As of January 2004, PWD may have been put into Spend-Down eligibility category	As of January 2004 through August 01 2005 (Prior to the institutionalization of the LAO2 prompt), PWD may have inadvertently been put into spend-down (now referred to as		- July 13 Concern was expressed as to what if anything can be done to capture persons who were missed. -Aug 15 Additional discussion occurred. No action - <u>OCT 10</u> There was some discussion as to what/who this population is. Linda Kusnier is working on the December 2003 persons that were spend down prior to January 2004

(now referred to as the Deductible Program) instead of being referred to the FTW eligibility category.	the Deductible Program) when applying for Medicaid benefits because of having earned income combined with unearned income that placed total earnings over the FPL. Some of these individuals should have been FTW participants.		and would have been FTW persons except for the implementation date. Tony was thinking this was the same group of persons. Logan will pursue with Linda
<b>AD Care Issue</b>  PWDs that come in to apply for Medicaid and are working below 100% FPL are automatically referred to AD Care.	It is the policy of DHS to place eligible individuals into the most beneficial MA category for the person. Yet, <u>some individuals with disabilities who have jobs and are actively working are placed into ADCARE rather than FTW</u> . These individuals have a combined income below FPL. The benefit of placing working PWDs to FTW would increase the program enrollment numbers and bring more federal grant dollars to the state ultimately providing greater opportunities to individuals with disabilities.	<ul style="list-style-type: none"> <li>-Take a look at DHS policy and procedures and determine if changes are needed. If so, make recommendations to MSA. Theresa and Jackie</li> <li>-Study the challenges of transferring working persons with disabilities from ADCARE to FTW to be sure that no harm would occur (recall that some would then need to pay the Part B premium of \$88.50/mo.)</li> </ul> <p>*People will only have to pay their Part B premium as their income rises above the poverty level. At that point they would no longer be eligible for ACARE or the Medicare subsidy because they would be over income.</p>	<ul style="list-style-type: none"> <li>-<b>April 11</b> Joe Longcor provided MSA with an official request to notify DHS of the transition of single working AD Care consumers to Freedom to Work. This will help increase the numbers of Freedom to Work consumers for the submission of the comprehensive grant. MSA will provide each county DHS with a list of possible consumers to transition. DHS will have to ascertain if the consumer is single, and if appropriate, change the coding to Freedom to Work. A complete case review should not be required. If DHS Outstate Operations sends the list to each county with a due date, these should be completed in time for the comprehensive grant submission.</li> <li>-<b>May 09</b> Logan Dreasky stated that there just was not the manpower to get the 6000+ transferred in the near future, but he did feel that the original 600 from the list that Dan from DHS came up with on the original list, who were erroneously in ADCARE have to be moved right away. The action would be handled by MSA personnel, although in the immediate future they were busy crunching numbers for the budget. Even so, Logan stated that he has the original hard copy around somewhere and that this could probably be done soon, about two months time. I said, "So then, we can expect that it will be completed by August 2007?" No response was given on commitment.</li> <li>One idea expressed as to getting the others transferred over was to have the MIG fund a staff position for a while to move the 6,600 ADCARE to FTW. This was just an idea that was suggested and discussed as a possibility to make the process more doable.</li> </ul>
<b>Freedom Accounts Issue</b>  FTW enrollees are not aware of Freedom Accounts and commonly don't know	The advantage to Freedom Accounts is that <u>PWDs can set aside income to save for things they need, and still qualify for Medicaid</u> benefits and medical coverage under the MA program.	<ul style="list-style-type: none"> <li>-Determine how to build awareness among FTW enrollees to promote increased earnings &amp; savings while retaining needed benefits.</li> </ul>	<ul style="list-style-type: none"> <li>-<b>Aug 15</b> Theresa reported that she has located within the PEMs a DHS Form that will serve the purpose of designating freedom accounts by consumers of DHS services. She also has drafted new PEM language and directions for the use of this form. Theresa is in the process of going through the PEMS to see where modifications need to occur to affected PEMs, and is drafting a memo on this to</li> </ul>

the benefits of utilizing these accounts to build savings or increase earnings.			<p>be submitted with the suggested changes.</p> <p><u>-OCT 10</u> Theresa shared a draft Bulletin announcing this policy. She provided Logan with a copy. MSA will review and provide the office with comments. Tony suggested adding a section on consumer responsibilities and consequences to the bulletin and the brochure he is working on. Theresa suggested modifying DHS Form 503 Asset Verification Form to include designation for Freedom Accounts, creating a new DHS Form for FTW. A suggestion occurred to modify the FTW DHS Form since Freedom Accounts can also include money from income. Make it a similar but New Form with its own Form Number.</p>
<p><b>SSA 1619 transition to FTW</b></p> <p>Presently smooth transition to FTW is not assured.</p>	<p><u>Persons</u> presently in 1619 status may earn or save their way onto FTW, but <u>are fearful to take that leap because they are unsure that transition</u> into FTW Medicaid <u>will be a seamless process.</u></p>	<p>-Research possible ways to address MA policy to allow this transition to be seamless.</p>	<p>-TBD</p>
<p><b>Working from Home and HUD Housing</b></p>	<p><u>Persons living in HUD housing are told that they cannot engage in business activities out of their home.</u> This severely limits some employment opportunities for PWDs.</p>	<p>-Theresa will check HUD policy and also with a few contacts she has within the advocacy field that often helps PWDs with housing issues regarding subsidized housing.</p>	<p>-June 16 Ref Jackie Blankenship (MSHDA) thru Sue Eby (MDCH) thru Glen Ashley (MDDC-MDCH)</p> <p><b>HUD Regulations:</b> 24 CFR 982.551 Obligations of Participant states</p>
<p><b>Michigan First - Health Care Program</b></p>	<p>Does this new waiver have any impact on the Freedom to Work Program?</p>		<p>-July 13 Jackie Tichnell contacted Susan Yontz. What we know so far is that it is an 1115 waiver, there is no draft available to share, and there is no template. Susan will let people know that we are interested in learning more information and she will get back to us.</p> <p>-August 8 Theresa has done some research into this and drafted a memo giving the message that from all materials so far there appears to be no adverse effects to FTW participants. This new MI health program may in fact offer health care to people with disabilities who wouldn't otherwise have access to health care.</p>
<p><b>FTW training in DHS offices (and elsewhere) to NOT include References to not being on a Spend Down/Deductible.</b></p>	<p>The current training module used by DHS makes reference to FTW not being for people on the deductible Medicaid program.</p>	<p>The fact of people being on a deductible being the reason for exclusion from FTW is really not true. The qualifying eligibility criteria used for FTW is the same as for ADCARE eligibility, using an SSI category income breakdown.</p>	



<b>Issue regarding the use of or Lack of use of IRWEs by PWDS due to many systemic problems.</b>	<p>1. There are no clear rules or process available to the public or with in the SSA Department that persons can use as guidance in determining whether they have potential IRWEs.</p> <p>2. When PWDS who are aware of the POMS or are working with a knowledgeable Social Worker and therefore they have a list of IRWEs to turn in. They are treated as if they are stealing or trying to get something they don't have a right to.</p> <p>3. When PWDs are working with knowledgeable WIPAs etc. and turn in there IRWEs, they receive no correspondence or feedback from SSA. And on most occasions no one even applies the IRWES to the case. And if SSA does. SSA never tells anyone.</p>	<p>There needs to be an administration process and documentation flow process put into place here. Along with an appeals process.</p> <p>The lack of these things clearly shows why the numbers are so low in people using IRWEs.</p>	
<b>FTW and Family Size Eligibility Issue</b>	<p>When FTW eligibility is considered for people with disabilities, we look at the individual. The issue of what is the individual is a member of a family of two and the working spouse is currently receiving Medicaid under ADCARE or some other category?</p>	<p>-We need to decide if we can look at family size relative to income eligibility.</p> <p>-We need to consider the impact on other people who now may be eligible where they were not before.</p>	<p>-<u>March 14, 07</u> Mr. Steve Fitton , and Mr. Paul Reinhart, and Ms. Jackie Doig were guests at the meeting this day to discuss this particular issue as it arose with a married disabled consumer who wished to be in the Freedom to Work category. Currently, he receives Medicaid through the ADCARE category. Between the consumer and his spouse their combined income is under the FPL income level for a family of two. Although the individual alone has unearned income above the FPL for an individual. The question was raised of whether or not to allow an individual who meets the 2 per person standard of unearned income less than 100% of FPL criteria into the FTW category. Paul supported it. Steve said he also would support it, but he would like to see some documentation on the implications of allowing this. Logan said that this would cause some issues with the way the law is written and with CMS and the State plan.</p>
<b>People Dropping Out of FTW....Why?</b>	<p>People deciding that they don't want to participate in Medicaid for whatever personal reason they may have.</p>	<p>Attend existing community gatherings the consumers and their families/support persons attend. Ask Why?</p>	

		<ul style="list-style-type: none"> <li>-Was the program difficult to participate in?</li> <li>-Were the rules too difficult to understand?</li> <li>-Was there no one to explain the program or help with paperwork?</li> <li>-Did they receive Benefits counseling/ If so, was it helpful?</li> <li>-If not? Why Not?</li> <li>-Did they not trust the program would work for them?</li> </ul>	
<b>Migration Issue</b> <b>(People moving out from one county and into another to become a Medicaid Beneficiary)</b>	<ul style="list-style-type: none"> <li>-People will migrate to counties based on the way DHS policies are applied to cases.</li> <li>-For example. An individual w/disabilities since birth; Medicaid eligible since birth; moves to another county and has case transferred. They are planning to stay in new county for awhile. (Cheap Rent). Person soon discovers that in new county they are not eligible. Why?</li> </ul>	<ul style="list-style-type: none"> <li>-Cost of Living varies from county to county. DHS Budgeting process for each county is based on the COL for that county. Therefore the individual may or may not be a recipient of the same benefits from county to county.</li> </ul>	



# Michigan LTC Connections

## Vision

**Each LTC Connection site is a highly visible and trusted source of information and assistance about long-term care, aiding Michigan residents with planning and access to needed services and supports, in accordance with their preferences**

## Report to the Legislature

Section 1686 of Public Act 330 of 2006 requires a report on the progress of Long-Term Care Single Point of Entry pilot projects. The Single Point of Entry Project was established as a result of the Governor's Executive Order 2005-14 issued in June, 2005, in order to implement recommendations made by the Governor's Medicaid Long-Term Care Task Force. In September, 2006 the SPE's were named Michigan's Long-Term Care Connections.

**Start up Activities:** Contracts were established with lead agencies in the four regional areas that were awarded SPE grants in June of 2006. These agencies have worked to develop independent SPE entities. Each site has a contingent of trained and knowledgeable staff. A curriculum of training was developed to ensure that the staff is well-informed and that consistent standards are implemented across regions. All of the regions have set up local offices and hired staff to begin operations. In addition, they have established independent governing boards and consumer advisory groups. Between January and March of 2007, the SPE's held 65 stakeholder meetings, 7 SPE Governing Board meetings and 6 Consumer Advisory Board meetings.

**Independent Entities:** In August, 2006 the department signed contracts with four demonstration projects to initiate the single point of entry programs. One of the priorities in the contract was to create separate, independently run, consumer driven entities that are solely responsible for the operation of the single point of entry program. The department is currently in the process of re contracting with these newly created independent entities. These contracts will be implemented with fewer resources than it was originally planned. As with other state contractors, the resources available to this project have been diminished as part of the

state's budget crisis. The state's freeze on hiring has been extended to the Long Term Care Connections. In addition, over the two year period of FY 07 and FY 08, the program's appropriation is expected to be reduced by \$8.7 million or 25% less compared to the initial proposal of \$34.8 million.

**Mandatory Level of Care:** This new law, in section 109i (17), also mandated that the SPE's serve as the sole agency within the designated area to assess a consumer's eligibility for Medicaid long-term care programs using a comprehensive level of care assessment. However, the SPE contracts had already been signed prior to the enactment of P.A. 634 at which time the SPE's were seeking a voluntary the level of care determination. The need for the SPE's to perform this new mandatory functional eligibility has been communicated to the Centers for Medicare and Medicaid Services (CMS). Policy and system changes need to be developed to perform this function and a target date for implementation of October 1, 2007 has been set.

**Core Services:** The implementation of SPE Core functions has been phased in over time. Beginning October 1, 2006, statewide Information and Assistance functions were initiated after being developed and refined by all four regions. In the first quarter of Calendar Year 2007, over 5,700 consumer calls were responded to for information and assistance. These calls include extensive discussions as staff worked with consumers to answer their questions which may require as many as 4 to 5 return calls. The staff use factual information to develop referrals and promote understanding of the web of services as consumers explore their options based on person centered planning (PCP). Long term care options counseling functions continue with over 300 option counseling cases opening in the first quarter of Calendar Year 2007. At the core of this PCP paradigm shift is the practice of putting the consumer in charge of their long term care life choices.

**Marketing and Outreach:** Marketing efforts have been made to make consumers aware of the single statewide, toll free phone number for contacting the SPE's. This number is: (866) 642-4582. The pilots are

collaborating closely with the 211 phone network where it exists in the state. The Long Term Care Connection networks are reaching out to providers, nursing facilities and hospitals to develop significant working relationships required to streamline access to information and guidance. The SPE's have conducted 253 outreach activities and held 28 community education presentations in the first quarter of Calendar Year 2007. The intent of these programs is to inform consumers of their options assists them to utilizing resources more efficiently as they may choose services more closely aligned with their needs. When consumers know their options lower costs may result.

**Information System:** The department and pilots have focused their efforts on the development of an information system across the provider network. This web-based electronic data system required the establishment of preliminary policies and processes for SPE core functions. This system continues to be refined to ensure that the data required by P. A. 634 will be collected consistently across regions. Over the past few months, all four entities have reviewed regional access practices to determine a baseline for improvement, as well as grasp a deeper understanding of the barriers and challenges in processes as consumers attempt to access Medicaid services. In addition, the system will include a resource data base with information on providers available over the web for consumers seeking services.

**Evaluation:** The department has contracted with an independent evaluator to assist in the analysis of implementation and outcome issues. This evaluation plan was submitted for review to Health and Human Services (HHS) under the Aging and Disability Resource Center (ADRC) grant. The department is now finalizing outcomes and identifying measures for evaluation. This process will include stakeholders, consumer systems and a performance evaluation of the four sites.

**Independence Plus and  
Money Follows the Person Grants**  
May, 2007

- The 2007 Michigan Self-Determination Conference will be on June 11 & 12 at the Lansing Holiday Inn South. Again this year, consumers are invited to sell goods and services from micro-enterprises. A “film festival” of disability related videos will occupy one of the breakout rooms. This is the 10<sup>th</sup> annual state wide conference.
- Materials from the Consumers as Employers, from the Paraprofessional Healthcare Institute course on “Employing, Supporting and Retaining Your Personal Assistant” can be found at this web address. <http://198.109.129.5:3455/sdl/74>
- The booklet written by Ellen Sugrue-Hymen, called “Hiring and Managing Personal Assistants” has been printed. This resource is intended for persons with disabilities and others in Self-Determined arrangements who hire their own staff. Copies can be requested through The Arc Michigan.
- Combined 1915bc Waiver Development - An internal draft of a concept paper describing the scope, purpose and methods for a cost neutral Medicaid benefit in one or two counties in support of community living options for elders and persons with disabilities is being developed. This document was sent to the CMS but there has been no response at this time. Meetings have begun on the feasibility study for the waiver. The waiver request is scheduled to be completed by October 1, 2007.
- No-cost 6 month extension requests have been sent to CMS for the Independence Plus and the 2003 Money Follows the Person grants. The extension period is for October 1, 2007 to March 30, 2008.
- The next meeting of the Self-Determination Implementation Leadership Seminar will be on July 10th.

## **LTC Supports and Services Commission**

Farmer acknowledged the passing of Commissioner James Francis-Bohr and asked Chaney to read a tribute she had prepared.

Governor has made appointments/reappointments.

- Appointment - Denise Rabidoux to the Commission. Ms. Rabidoux is a registered nurse, and has spent her entire career in long-term care. She was appointed to represent direct care workers.
- Reappointment - Kilde was reappointed to the Commission, this time to represent primary and secondary consumers.

Commission advocacy activities continue to focus on the state budget. There was much discussion regarding the budget and what the Commissioner could do as advocates/consumers. Paul Reinhart, Medicaid Director discussed a pending letter that notifies providers of delayed payments for FY 07. Advocacy for revenue as part of the solution is critical, per Reinhart.

Several persons presented educational information on the Single Points of Entry for the Commissioners. This included Susan Steinke for an overview of Workgroup A of the Medicaid Long-Term Care Task Force. Susan Martin provided an overview of the development process for Public Act 634. Michael Head and Nora Barkey provided an overview of the demonstration initiative, including the contracting process and roll-out activities. Copies of their presentations are available at <http://www.michigan.gov/ltc/0,1607,7-148--143908--,00.html>.

Farmer requests Commissions ramp up their advocacy for revenue enhancements.



## **Systems Transformation Grant**

We presented our draft Strategic Plan to CMS on 4/25/07. The presentation went well and the CMS representatives were very positive. We received their written feedback with recommendations for the final plan. There are numerous general recommendations for all states and four recommendations specific to Michigan. We need to clarify some timelines, define some terms and address a couple issues in our evaluation plan. CMS emphasized the need to have a project director in place before we begin implementation. We are seeking an exception to the hiring freeze for that position. We will be making the changes and submitting a final plan by June 15.

By August 3 we must submit a complete evaluation plan. We will draw upon some of the members of the original three workgroups to provide input to the evaluation plan.

## **Deficit Reduction Act/Money Follows the Person**

### **DRA MFP Rebalancing Initiative:**

An internal workgroup has been reviewing the financial reporting requirements and the requirements for an Operational Protocol (our description of transition services in Michigan). Much of this already exists, so we are gathering that information now. We will be initiating a stakeholder group to continue the Operational Protocol development in the next couple weeks. This group will include consumers, providers (MI Choice, single point of entry, nursing facilities, Home Help) and state staff.

We also need to hire a project director for this grant before we can begin implementation. That position is being processed along with the STG position.

# **Self-Determination in Long Term Care Project**

## **Michigan Quality Community Care Council**

No Reports Provided

# When CPIGs Fly

Nicole Lomerson, MPH  
Erin McGaffigan, MSW, LSW

Darlene O'Connor, PhD  
Kimberly Wamback, BS

February 2007



**Meaningful Consumer  
Involvement in Systems Change**

# In Memoriam

## Irene Carkin 1936-2006

This report is dedicated to Irene Carkin who, at the age of 69, left a nursing home and moved into her own apartment. In her last year, Irene was an active member of the CPIG and a strong spokesperson for systems change.



## 10 Key Lessons About Meaningful Consumer Involvement

1. Involve people with disabilities as early as possible to ensure meaningful involvement.
2. Develop an atmosphere of trust and collaboration. In this climate, both consumers and state partners will learn much from one another.
3. Offer reasonable accommodations to ensure meaningful consumer involvement. Assure that accommodation needs are met, but empower consumers to assist in the process, rather than simply expecting others to make arrangements for them.
4. Provide support for facilitation and documentation of progress.
5. Enable consumers and state partners to participate as equal partners in policy discussions. More effective policy will arise from such a dialogue.
6. Struggle for consensus rather than simply assert the power of the state or the power of the majority vote. The process of coming to consensus helps both sides to listen to one another and truly hear their concerns.
7. Connect policy and research agendas with the real-life experiences of people with disabilities.
8. Maximize resources by creating cross-disability policy rather than policy through disability silos.
9. Work intensively to sustain successful initiatives.
10. Believe that systems can change, and CPIGs can fly!

## In the beginning...

In June 1999, the Supreme Court issued a ruling in a case known as the “Olmstead Decision.” This decision reinforced the responsibility of public entities to offer programs and services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Following this ruling, the President’s New Freedom initiative intensified federal and state activities to support people with disabilities in the community.

Under the New Freedom Initiative, the Centers for Medicare and Medicaid Services (CMS) released a series of Real Choice Systems Change grants, beginning in 2001. With the Real Choice grants, CMS expected states to engage people with disabilities actively in all phases of the grant implementation. CMS required that grantees establish “consumer advisory committees” as part of this involvement.

Massachusetts was among the first states to receive a Real Choice grant. Like many states, Massachusetts took a while to start the grant activities. The key state agencies involved in the grant did not agree to establish the consumer committee until early in 2003, over a year after the grant funds had been awarded.

During the early grant period, people with disabilities and advocates became frustrated and angry about the lack of meaningful consumer involvement. A low point was reached in January, 2003 when the first public meeting of the grant was held.

Consumers and disability advocates voiced their dissatisfaction with the lack of involvement and pressed for the establishment of the consumer committee. Consumers said that they would advocate the return of the funds if meaningful consumer involvement was not established. From that point forward, a cautious partnership between consumers, state partners, and the grant staff began to evolve.

The work of this collaboration did not always progress smoothly. Many setbacks were experienced by all parties. However, as the end of the grant drew near, key stakeholders looked back and realized that significant progress had been made. They decided to document lessons learned for policy makers and other stakeholders through this report and a companion video.

“



The question was, 'If this is going on like this, why are we coming on board so late? And if it is written for us, why are we not part of the implementation process?'

—Emeka Nwokeji, CPIG member



## Nothing about us—without us!

Consumers remember the first public forum in January 2003 as the “Real Choice Revolt.” They acknowledge that emotions and tempers were running high that day. Grant staff at the UMass Medical School’s Center for Health Policy and Research (CHPR) had organized the meeting with the intention of introducing the five grant areas to consumers, and eliciting feedback. However, consumers were upset that they had not been “meaningfully involved” earlier in the planning of the grant activities.

The night before the meeting, several consumer advocates had gathered together. They asked: “Why don’t we see if we can do something right out of the gate?” The next day, soon after the forum began, a note was passed among consumers advocating they take a stand. Grant staff and state representatives soon realized that consumers were frustrated by the long history of minimal involvement and expectations.

“There was anger in their voices [at the forum]. I could tell this grant was more than just a grant from CMS,” said one grant staff member. “Instead it was symbolic of all the grants that came before, all the services cut, all the plans not implemented and historical lack of involvement of real consumers in the development of policy that affected their lives. I knew we were going to have to pay for this history.”



And that was the cry, ‘nothing about us, without us,’ and we said this can’t continue. So, it was stopped. We had a break. We went out in the hallway and were followed by a phalanx of state bureaucrats and academics—UMass people.

—Charlie Carr, CPIG member

”

## Meaningful consumer involvement: The CPIG and the Collaborative Team.

During the break at the January forum, grant staff, state agency representatives and consumer leaders agreed that they needed to set up the consumer committee. After the break, they asked participants to volunteer for a Nominating Committee to propose members for the consumer group to guide the grant. The Nominating Committee wanted to assure that this consumer group would have a meaningful role in the grant. They didn't want a traditional advisory committee model.

Many consumers had been part of consumer advisory groups in the past and sometimes referred to them as “punch and cookie groups.” Consumers felt they were being treated as tokens in these groups. They received refreshments, got updates, and provided recommendations. But later they often found that their advice was ignored. Consumers participating at the January forum wanted to make sure this did not happen with the Real Choice grant.

Creating the Consumer Planning and Implementation Group (CPIG) was an attempt to assure meaningful consumer involvement rather than simply an advisory group. Consumers wanted serious involvement in the planning and implementation of the Real Choice grant and even the group's name reflected it.

Consumers wanted to be directly involved in the direction of the Real Choice grant. They wanted to come to the table as equal partners rather than simply as advisors whose input might or might not be taken into account.

The name of the group became important as a symbol of this level of involvement. The group was a Planning and Implementation Group—a PIG—not an advisory committee. The pig became a mascot for the group. One of the co-chairs found a heavy metal pig with wings that she brought to an early meeting. Someone in the group coined the expression “the system will change when CPIGS fly.” The flying pig presided over the meetings for the next two years and represented both the challenges and possibilities of change.

“Consumers were involved [in the grant]. That was the real difference.”  
—CPIG member

The group also wanted state partners and grant staff to “respect that individuals with disabilities can control their lives,” says one CPIG member. “[They’ve been] doing programs for themselves for years and should have been expected to come to the table with experience.”

The CPIG requested that grant staff not attend their first few meetings. This gave them time to form as a group and educate one another. They felt the state and grant staff already had their time to work on the grant. Consumers wanted time to formulate their own ideas as the others had done.

“We told them not to come to these meetings. They weren’t welcome in the beginning until we got our proverbial act together.”—CPIG member

Grant staff struggled with this “request.” Ultimately they decided that it was more important to establish trust and give the consumers control of their own preparation than to refuse the request. They agreed to come for only the last hour of the full-day meetings.



Both [consumers] and state partners found out that we were trying to work for the same causes and challenges.

—Anne Fracht, CPIG member

Once the CPIG members were ready to reconvene with the state partners, a process for decision-making was needed. CPIG members and state partners recognized that it would be difficult to make decisions with state partners and the CPIG group in its entirety.

So, the CPIG chose five consumers to join five state partners. This ten-member group became the Collaborative Team, the decision-making body for the grant.

“We needed a decision-making body that would deal with conflict between consumer views and state means [and] we wanted to talk with the state directly.”—CPIG member

State partners agreed “it made sense to have a small group steer the project.” From the beginning, Collaborative Team members agreed that decisions would be reached by consensus. The process of reaching consensus was viewed as a strength by members of the CPIG. The consensus process “was good because it forced issues” that may have otherwise been tabled, said a CPIG member.

The Collaborative Team met monthly to provide direction on the Real Choice grant activities. They revised the goals of the grant. They adopted the pilot project which the CPIG had recommended. The pilot project was a variation on the national Cash and Counseling Demonstration Program. It allowed Massachusetts to offer individual budgets to a small group of consumers diverse in age and disability. This experience strengthened the state’s ability to develop a statewide model.

The CPIG eventually moved to a quarterly meeting schedule. They provided input and received updates through the Collaborative Team’s consumer partners. Consumer involvement through the CPIG and the Collaborative Team ensured that consumers were involved in all decision-making aspects of the grant activities.

## How do you define accessibility?

The members of the CPIG had a variety of accessibility needs to fully participate in meetings. Grant staff provided accommodations at the first few meetings of the CPIG. However, CPIG members criticized the level of accommodation.

It took time for grant staff to learn about the various accessibility needs of CPIG members. Several CPIG members admitted to treating grant staff harshly where accommodations were concerned.

“[CHPR] took hits early on about not having materials in an accessible format.”—CPIG member

However, the struggles with accommodations were short-lived. Grant staff soon became adept at providing consumers with what they needed. The staff “was receptive to member recommendations, member needs, persevering in procurement of materials, support services, and generally interested in feedback,” says a CPIG member.

“Once we instructed them, they did it with no prodding.”  
—CPIG member



We put [grant staff] through the paces at the first meeting... it was a real wringer process.

—Sandy Houghton, CPIG member

State partners recognized that staff support for the meetings was critical to the success of the process. Grant staff agreed, and also felt that they had learned much from the CPIG's high expectations.

“I was unaware then of how the term ‘accessibility’ meant so many different things to different people. Once all individuals’ accessibility needs were met and grant staff was aware of those needs, meetings became much more effective.”—Grant staff



[Grant staff] was good about making sure we had agendas and materials; without their role in the process it would have been tough.

—Margaret Chow-Menzer, State partner

”

## Are we diverse enough yet?

Participants mentioned many strengths of the CFIG model. However, the most common theme to emerge was the strength of its diversity across age and disability. The CFIG came to represent persons of all ages with a variety of disabilities.

The diverse nature of this group was a strength as well as a challenge. Individuals who were able to articulate issues related to their own disability were often less sensitive to the accommodation needs of others. CFIG members sometimes needed to be reminded to slow down, to avoid using technical terms, and to explain things that were not familiar to the whole group. In addition, some CFIG members had more advocacy experience than others. This led to more experienced advocates dominating early meetings, while others struggled with being heard.

“Other groups are not as far ahead as the independent living movement, and their voices may be overshadowed by others who are stronger advocates.”—Grant staff

Over time, CFIG participants with historically underrepresented disabilities (such as sensory impairments, developmental disabilities and mental health disabilities), as well as other underrepresented groups (elders and minorities) were heard and accepted at the table as equals.



The broad representation on the CPIG resulted in a greater understanding of that population at a more global level by CPIG members, such as:

“The MR/DD (Mental Retardation/Developmental Disability Community) network has been accepted and now noticed.”

“There was respect for minority contributions across race, age and disability.”

“I really loved to see some of the newer people at the table. Particularly people that typically were not involved in cross-disability work. People with head injuries, people with cognitive disabilities, that we hadn’t done good work with over the years. Having them at the table was great. Seeing them become empowered.”

In addition, consumers felt that the diversity of the CPIG was an accurate representation of the disability community.

“[The CPIG represented] everybody that would benefit from home and community-based services, families, providers, consumers, and spouses... beyond those of us sitting at the table.”—CPIG member

Several CPIG members acknowledged the benefit of feeling accepted by other members of the CPIG who may have had much more experience with activism. CPIG members described this as:

“Being accepted for myself”

“Becom[ing] part of the family”

“[Feeling that] I had arrived” [after being elected as a co-chair]



[Persons with disabilities have] more in common than we do in difference.  
—Keith Jones, CPIG member

Consumers and state partners agreed that creating policy across age and disability was the best approach. This allowed for strength in numbers, the cost-effective utilization of scarce financial resources, and the ability to build consensus on policies that eliminated the traditional silos. The cross-disability approach increased the strength and legitimacy of the grant effort. Participants mentioned several reasons for working across disability:

“In the past, there has been ‘competition’ between disabilities because they are fighting for a very small piece of the pie.”—State partner

“It’s better to compete for large pieces together than small pieces for each. [It’s not a] more for you less for me approach; we all get more.”—CPIG member

“This was as cross-disability as it gets ... Increased power and common level of understanding are two major reasons that people with disabilities may want to do cross-disability work. It helps to strengthen budget requests with more constituents. It helps to change policy if you have a larger voice.” —State partner

Consumers recognized that it is easy to focus only on accommodations for visible disabilities. They advised future CPIG groups to be as inclusive as possible by providing a wide array of accommodations to support people with various disabilities. They emphasized the accommodation needs of persons with cognitive disabilities. These include increased reading time and the need for support persons for coaching or clarification.

One state partner also noted that mental illness is cyclical in nature, with symptoms that wax and wane over time, while other disabilities could be static. Not taking this important difference into account could do some consumers a disservice. State partners, like consumers, recognized that needs related to various disabilities should be addressed. However, initially some state partners had difficulty communicating during the Collaborative Team meetings in ways that all consumers could understand.

“The way that [state partners] shared information was less accessible to some [consumers]. State partners would talk amongst themselves at the table sometimes.”—State partner

However, all participants overwhelmingly supported and encouraged taking a cross-disability approach to policy design and implementation.

As one CPIG member put it, “If you work together ... you’re so much more dynamically strong, [which results] in a project that has much more of an impact.”

“



If there are issues that cut across-disability, then cross-disability policy does make sense.... [it would be] nice if we could do it more often, nice to have a single option rather than five.

—Michael O'Neill, State partner

## Communication, collaboration, consensus.

At the beginning of the Real Choice grant, state partners and consumers distrusted one another. The grant's mandate for meaningful consumer involvement helped to push the state to engage with consumers. However, the delays in establishing the process for consumer involvement worsened the distrust in the first couple years. Participants had to reestablish trust to move forward.

“Because of a lack of communication, I think there was some suspicion that we were trying to do things that ... other people couldn't support. And so, we really had a communication expectation—challenge.”

—State partner

Grant staff served as facilitators for CPIG and Collaborative Team meetings. At times they seemed to be targets of frustration that was meant for the state partners or other stakeholders. Staff recognized that a successful process depended on transparency. Consumers and state partners needed to know the grant staff's intentions and needed clarity about the grant staff's role in the process for this effort to thrive.

“Being transparent [worked]. I find that people tend to pick up on your intentions even before you do... so trying to be something you are not does not help anyone.”—Grant staff

Eventually, consumers and state partners perceived the staff role as an unbiased facilitator for the collaboration. One CPIG member described grant staff as: “Coming from a middle ground perspective, by virtue of being academics,” and as “not having an axe to grind.”

Because both the state and consumer partners were extremely busy, the grant staff sometimes stepped in to move the process forward. But staff soon learned that grant activities could not progress unless the consumers and state partners were as invested as they were, and equally committed to the work.

In the first year, miscommunications among all parties were common. To foster communication between the Collaborative Team and the CPIG, Collaborative Team meeting summaries were sent to the entire CPIG soon after each Collaborative Team meeting. Additionally, after each Collaborative Team meeting, one of the consumer representatives circulated a “hot topics” e-mail to the CPIG members. These methods helped to address problems and misunderstandings.



The members of the joint Collaborative Team were able to work through their differences by sticking with it and educating each other about their perspectives. Over time, a solid working relationship developed based on trust and respect ... rarely has a group, in my history, stuck it out to develop such a strong bond and mutual commitment.

—Debra Kamen, State partner

Several consumers were frustrated that the state partners involved were not always able to make decisions. This was particularly challenging when decisions involved the commitment of resources to sustain services to pilot participants at the end of grant. Consumers felt this slowed down the process, because state partners had to take information from the Collaborative Team meetings to a higher level before making commitments.

“The state partners in small decision-making groups didn’t have the power to make decisions,” says one CPIG member. Another member agreed, “If decision-makers were at the table, we could have gotten it done a lot faster.”

Eventually, through communication and the building of trust among consumers, grant staff, and state partners, the collaborative effort began to succeed.

Taking time to communicate and build trust was a key factor in the success of the grant.

“I really feel very strongly that this was one of the most productive and satisfying experiences that I’ve had. I think one of the most important things about that experience is that it became clear to all participants that we had much more in common than we had differences.”—State partner



I learned a great deal about the politics and pressure that the State has to work under.

—Robert Snierison, CPIG member



# Sustainability is not a four-letter word!

A key accomplishment of the CPIG and the Collaborative Team was the development and implementation of a pilot project to offer consumer-directed supports to a diverse group of people with disabilities. Before the Collaborative Team could reach consensus to implement the pilot, members discussed the need to sustain the pilot project beyond the grant period.

Consumers were concerned about the future of pilot participants after the completion of the grants. They raised ethical concerns about participants losing benefits when grant funds ended. They wanted to ensure sustainability for the pilot participants after the grants' completion. State partners also agreed that sustainability was important even though it took a long time before they could confirm a commitment from their agencies. When consensus was finally reached, all participants felt good about the outcome.

“What I remember the most was two or three state partners rallying with the disability side demanding that the sustainability portion be put into place. And, I think those people had an epiphany. And the epiphany was that this is unconscionable if we don't [sustain the pilot].”—CPIG member

In addition to sustaining the direct services developed with the Real Choice grant, participants recommended that the consumer involvement method also be sustained.

“The model, bringing consumers to the table to have a voice in the planning, implementation, and evaluation of elder and disability policy, is essential. For as long as a respect for this process is found in new grants and new initiatives, we have sustained the model.”—Grant staff

## Lessons learned:

Several lessons have clearly emerged from this systems change work. The first is that it is important to involve consumers from the very beginning in the research and policymaking processes.

“Get people with disabilities involved early—that’s it.”—CPIG member

Consumers weren’t the only participants to come away with a new perspective on the impact of collaboration on policymaking.

“A single important lesson is not to wait for a grant to bring folks together to make systems change. That process should be the foundation from which everything else flows.”—State partner

Another lesson was that grant efforts should address the disconnect between the real-life concerns of persons with disabilities and the priorities of policymaking and research. One participant believed strongly that the focus of grant activity should have been on direct services to individuals rather than the bureaucratic process of changing policy.

“Using money to get people services they need is where we need to put the money, not into more pilots.”—CPIG member

Most consumers gained great insight into the workings of state policy (both positive and negative). They became increasingly comfortable with couching arguments and discussing issues with state partners.

“[It was] good to have state partners there to help policy work. Many times they are fighting for the same things we are.”—CPIG member

State partners and grant staff also felt they had learned a lot:

“We could learn to do better... there is a big rush when grant money becomes available. We should involve consumers from the beginning, but it’s hard. Pulling in consumers three quarters of the way through makes their input limited in its impact.”—State partner

“[This] very assertive, opinionated (and sometimes aggressive) representation of disability advocates kept pressing for the best. We would not have gotten anywhere near where CHPR is now in terms of the accessibility and awareness of meaningful involvement if they were not as strong as they were.”  
—Grant staff

At the close of the project, most participants were able to look back and see that progress had been made in spite of what had seemed to be insurmountable odds.

“When I started, the state and consumer group were not meeting in one room, never mind sitting at the table to discuss policy,” says one grant staff member. “Now consumer and state partners are presenting together at state conferences and national conferences. They joke together about the ‘revolt.’ State partners [now] think about a method to seek consumer input on policy well before the implementation phase.”

“There are groups already in place that the state knows they can tap into rather than just talking to one or two specific advocates in hopes that they are representing a larger voice,” a grant staff member says. “I think people tend to forget all this change in the fear of losing ground. But it would be nice to instead recognize this progress in the hope of growth.”



I learned quite a lot from participating on a different plane, a different level with consumers than I had previously....It was just very gratifying to recognize that the perspective or the approach of the consumers and advocates was really very much the same, and the concerns were very much the same. So, it was a validation of my personal belief that we can accomplish a great deal more by working together than we can by just focusing on our differences.

—Ellie Shea-Delaney, State partner

## Where do we go from here?

The message of this report is neither that consumers should control policymaking nor that policy makers need more token advisory committees. The final lesson of this work is that policy makers can make more effective policy when they meet with consumers as equal partners at a common table, establish a trusting dialogue, and build consensus for positive change.

Rather than mandate advisory committees, federal and state officials should consider mandating PIGs—Planning and Implementation Groups—with Collaborative Teams to help them fly.





People should look at this very, very carefully and learn some lessons about how you interface with the bureaucracy—how you really get systems change to occur in a mammoth system.

—Paul Spooner, CPIG member

## Executive Sponsors



"The Real Choice pilot gave us rich and unique opportunities to promote consumer empowerment in our long-term support system in Massachusetts. We were able to test and refine an innovative consumer directed model which we will use as a foundation for our broader community based services 1115 waiver program for elders and persons with disabilities. We have learned and grown with the pilot and know that we will implement something truly effective."

Gerald J. Morrissey, Jr., Assistant Secretary  
Office of Disabilities and Community Services  
Executive Office of Health and Human Services



"I am very pleased to have my agency participate and support this important effort to promote meaningful consumer involvement in our programs. I believe the work that was done by consumers, advocates and state officials is an excellent example of how we can accomplish important goals when all collaborate and work together."

Jennifer Davis Carey, Secretary  
Executive Office of Elder Affairs

### **CPIG Members**

**Gigi Alley**, Advocate

**Reggie Clark**, Advocate for persons with  
visual impairments

**Rita Claypoole**, Elder advocate

**Deb Davidson**, Advocate

**Anne Fracht**, Mass Advocates Standing Strong

**Sandy Houghton**, Developmental Disabilities  
Council

**Keith Jones**, Advocate

**Rick Malley**, Mass Office of Disability

**Carol Menton**, Mass Commission for the Deaf  
and Hard of Hearing

**Jenifer Mitsch**, Caregiver, Parent and Advocate

**Emeka Nwokeji**, Advocate, Mass Rehabilitation  
Commission

**Rob Park**, Boston Center for Independent Living

**Edna Pruce**, Boston Senior Home Care and  
Mass Brain Injury Association

**Charlie Sisson**, Coastline Elderly Services

**Robert Snierston**, Disability Policy Consortium

**Paul Spooner**, Metrowest Center for  
Independent Living

### **Emeritus Members**

**Charlie Carr**, Northeast Independent Living

**Deni Cohodes**, Advocate

**Susanne Doswell**, Advocate

**Chris Griffin**, Disability Law Center

**Lou Nisenbaum**, Mass Families Organizing  
for Change

**Sonya Perduta Fulginitti**, Advocate

**Phil Zukas**, Advocate for persons with  
visual impairments

### **Collaborative Team Members**

#### CPIG Representatives

**Keith Jones**, CPIG Co-Chair

**Edna Pruce**, CPIG Co-Chair

**Anne Fracht**

**Sandy Houghton**

**Charlie Sisson**

#### State Partners

**Laurie Burgess**, Executive Office of Health and  
Human Services

**Margaret Chow-Menzer**, Department of  
Mental Retardation

**Debra Kamen**, Mass Rehabilitation Commission

**Michael O'Neill**, Department of Mental Health

**Ellie Shea-Delaney**, Executive Office of Elder Affairs

### **Emeritus Members**

**Gigi Alley**, Advocate

**Charlie Carr**, Northeast Independent Living

**Deni Cohodes**, Advocate

**Betty Ann Ritcey**, Executive Office of Health and  
Human Services

### **Real Choice and Independence Plus Grant Staff**

**University of Massachusetts Medical School  
Center for Health Policy and Research (CHPR)**

**Erin (Barrett) McGaffigan**, Project Director

**Nicole Lomerson**, Evaluator

**Emma Quach**, Evaluator

**Kim Wamback**, Research Coordinator

**Darlene O'Connor**, Co-Principal Investigator

**Jay Himmelstein**, Co-Principal Investigator  
and Director, CHPR

**Photography by:** Luigi Piarulli, Multimedia Technology Group, UMass Medical School



This report was prepared by the University of Massachusetts Medical School's Center for Health Policy and Research (CHPR) in conjunction with the Massachusetts Real Choice and Independence Plus grants. We want to express appreciation to the members of the Consumer Planning and Implementation Group (CPIG), the Collaborative Team and the Nominating Committee for their openness in sharing comments about this process.

Special thanks go to the following CPIG members who helped design this study:

Anne Fracht  
Carol Menton  
Robert Snierston  
Sandy Houghton

The report is funded through the Centers of Medicare and Medicaid Services. It was developed under grant CFDA 93.779 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services or endorsement by the Federal Government.

This report is available in alternate formats upon request. For more information, please contact Nicole Lomerson at: [Nicole.Lomerson@umassmed.edu](mailto:Nicole.Lomerson@umassmed.edu), or 508-856-1758.





222 Maple Avenue, Shrewsbury, MA 01545-2732  
Tel. (508) 856-7857 Fax. (508) 856-4456  
[www.umassmed.edu/healthpolicy](http://www.umassmed.edu/healthpolicy)  
[healthpolicy@umassmed.edu](mailto:healthpolicy@umassmed.edu)

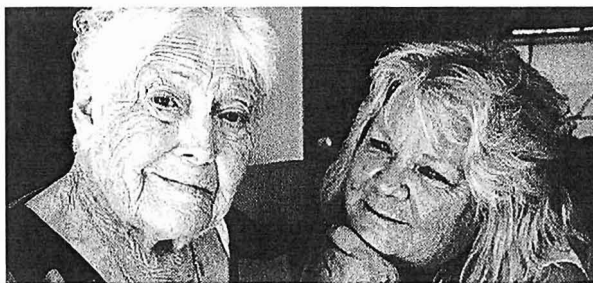


CWMCHPRV1 02/07-2

**Office of Long-Term Care Supports and Services**  
**Contact List**

	<b>Office Phone</b>	<b>Duties</b>	<b>E-Mail Address</b>
Jane Church	241-9173	SPE, LTC Commission support	<a href="mailto:churchja@michigan.gov">churchja@michigan.gov</a>
Joe Longcor	241-1730	MIG grant, project manager	<a href="mailto:LongcorJ@michigan.gov">LongcorJ@michigan.gov</a>
Mike Daeschlein	335-5106	STG grant, DRA/MFP grant	<a href="mailto:daeschleinm@michigan.gov">daeschleinm@michigan.gov</a>
Nora Barkey	335-9842	SPE, ADRC, project manager	<a href="mailto:barkeyn@michigan.gov">barkeyn@michigan.gov</a>
Rob Curtner	335-8710	IP, LTC Prepaid Health Plan, project manager	<a href="mailto:curtnerr@michigan.gov">curtnerr@michigan.gov</a>
Tari Muñoz	335-5671	Self-Direction in MIChoice, project manager	<a href="mailto:munizt@mi.gov">munizt@mi.gov</a>

If you have any trouble with acronyms, call me



Robert Wood Johnson Foundation

## Who We Are

Michigan is a participant in *Cash & Counseling*, a national program funded jointly by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services. *Cash & Counseling* offers Medicaid consumers with disabilities more choices about how to get help at home or in their communities. The program gives frail elders as well as other adults and children with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs. *Cash & Counseling* participants may use their allotted funding to hire their own personal care aides as well as purchase items or make home modifications that may help them to live more independently.

## Cash & Counseling In Michigan

Michigan's program—*Self-Determination in Long-Term Care*—is administered by the Office of Long-Term Supports and Services, housed within the Michigan Department of Community Health. Michiganders eligible for the program are the elderly and adults with physical disabilities covered by Michigan's "MI Choice" waiver. This program began enrolling participants in December 2006 and is expanding rapidly. In this initial phase, the program is available in four "pioneer" sites, covering Michigan residents in 26 counties. These four sites are: Burnham Brook (covering Barry, Berrien, Branch, Calhoun, Cass, Kalamazoo, St. Joseph, and Van Buren); the Detroit Area Agency on Aging; the Tri-County Office on Aging (covering Ingham, Eaton and Clinton); and the entire Upper Peninsula. It is anticipated that the program will expand state-wide in the coming months.

## Contact

Tari Muniz  
Project Coordinator  
Office of Long-Term Care Supports and Services  
Department of Community Health  
109 Michigan Avenue  
P.O. Box 30915  
Lansing, Michigan 48909  
(517) 335-5671 [munizt@michigan.gov](mailto:munizt@michigan.gov)

To find out more, go to [www.rwjf.org/longtermcareoptions](http://www.rwjf.org/longtermcareoptions) which highlights the Foundation's 25 years of innovative work in long-term care.

## The Challenge

In the early 1990s, the confluence of three trends pointed toward the need for a new direction in delivery and financing of long-term care services: 1) the number of people with age-related disabilities was on the rise (especially when viewed against a backdrop of a rising average life expectancy); 2) people with disabilities preferred autonomy in decisions about long-term care; and 3) government resources for long-term care were being spread more thinly.

The Medicaid program, at the time, restricted its coverage for supportive services at home to assistance provided by licensed agencies. The *Cash & Counseling* program, initially a three-state demonstration, would provide Medicaid-eligible adults the opportunity to manage a cash allowance and direct their own personal assistance services.

## The Model And Its Key Elements

Eligible consumers receive a comprehensive assessment and subsequent care plan with an assigned dollar value. The consumers are then provided with sufficient information to choose between managing an individualized budget and their own services, or going the traditional route with services and financing coordinated directly by the Medicaid agency. If the individual consumer decides to manage his or her own budget and care planning then the consumer, together with an assigned counselor, develops a spending plan to meet his or her personal assistance needs—essentially help at home with daily activities like bathing, dressing and cooking. This plan can also include equipment and services that increase a participant's independence or ability to manage a disability. The counselor is also available to help the consumer identify care assistants and access available community resources.

## Successes

Emblematic of Michigan's Self-Determination in Long-Term Care program's great success is the story of Ed who went without needed personal care services for four years. Distasteful of the idea of strangers in his home, Ed wouldn't hire anyone to assist him. Today, his daughter helps him with activities of daily living, because as a result of this program she can be paid for these efforts.

On a national level, an independent evaluation done of the initial three-state demonstration concluded that the *Cash & Counseling* program:

1. improved the quality of life for participants;
2. reduced participants' unmet needs for care and maintained health; and
3. significantly improved the lives of participants' primary caregivers.

The evaluation showed that the overall costs to Medicaid were somewhat higher for program participants but that savings in other Medicaid long-term care costs helped to offset the higher personal care costs. Participants began to receive the quantity and quality of care they needed all along. In sum, findings show that *Cash & Counseling* programs can be implemented successfully by states to serve populations with various disabilities and in various age groups, thereby increasing beneficiary satisfaction and improving disability-related health outcomes, and these programs need not cost Medicaid more than traditional services. Today, based on the encouraging results from the initial three states, *Cash & Counseling* programs are being implemented in 12 more states.

## Looking Forward

At least partially because of these documented successes, the Federal government recently made it easier for all states to introduce a *Cash & Counseling* option. As a result of passage of the Deficit Reduction Act of 2005, which amends the Social Security Act, as of January 1, 2007 states can now offer the *Cash & Counseling* option within their regular state Medicaid plans without first obtaining a waiver.

As the nation's population ages, it will become increasingly important to develop and strengthen community-based long-term care systems and public policies that promote consumer choice, caregiver support and quality care.